



Health Communication Evaluation Services

Task 36
Formative Research
Regarding Immunization Registries

Findings of Focus Group Research on Immunization Registries

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EXECUTIVE SUMMARY

Purpose of the Study

The National Immunization Program (NIP) contracted with Westat to conduct 20 focus groups plus a pilot group with various racial and ethnic groups in diverse areas of the country. The focus groups were convened to discuss parents' reactions to immunization registries, specifically the issues of content, access, and ways a child's immunization record gets into a registry.

The research was designed to obtain the following information from participants:

- Reasons why and why not to have a child immunized;
- Reactions to things a registry can do;
- Reactions to the content of the registry;
- Opinions about who should and should not have access to the information in the registry;
- Reactions to the primary ways that a child's immunization record can get into the registry;
and
- Perceptions of the most important benefits and risks of an immunization registry.

Method

A pilot focus group was conducted in Rockville, Maryland on September 9, 1998. The purpose of the pilot was to test the moderator's guide. Changes to the guide that resulted from the pilot included the rewording of questions, deleting questions, adding questions, reordering the sequence of questions, and providing more factual background information about registries.

The 20 groups were conducted from September 14 to October 27, 1998 in various regions of the United States – Ankeny, Iowa; Baltimore, Maryland; Tucson, Arizona; Tulsa, Oklahoma; Portland, Oregon; Pasadena, California; and Miami, Florida. NIP and Westat chose these locations to include a variety of geographic regions, and a diverse ethnic and racial mix. Sessions were held with persons representing five major ethnic groups--Hispanic, African American, American Indian, Asian/Pacific Islander, and non-Hispanic white. There were four Hispanic focus groups, two each in Tucson and Miami. There were four African American groups, two in Baltimore, and one each in Portland and Miami. Four

non-Hispanic white groups convened in Portland, Ankeny, and Baltimore. Four Asian/Pacific Islander groups were conducted in Pasadena and there were four American Indian groups, two each in Tucson and Tulsa. Two of the Hispanic groups were conducted in Spanish and two of the Asian/Pacific Islander groups were conducted in-language. The moderator for each group was of the same racial/ethnic group as the participants in the group.

Prior to the focus groups, participants were screened using several specific criteria. All were parents or legal guardians of at least one child under the age of six and said they were involved in making decisions about the health care of children living in the home. Recruiters also screened for education level in order to stratify the groups. The lower educated groups consisted of participants with a high school diploma or GED or less; and the higher educated groups consisted of participants with some post high school education, but not necessarily a college degree. Individuals with technical training coursework or technical training certificates also qualified for the higher education groups.

Summary of Findings

- **Most people had a generally positive initial reaction to the idea of an immunization registry, but some people voiced their concerns about issues such as the accuracy and privacy of the data.** Participants in virtually every group commented that registries sound great and are a good idea. Many expressed their delight with the fact the registry could send out automatic reminder notices. But some individuals who expressed general support for the registry, also called the system a “fail safe,” meaning it is a source of information if parents lose their own records. The concerned participants wanted to know if only the health care professionals who care for their child would have access or if all doctors would be able to view their child's record. Many were also curious about who was entering the data.
- **Initial reactions to the content of the registry were generally positive, although some people questioned the need for some of the information or wondered if the information could be misused.** Overall, the content was generally well accepted and the majority of participants mentioned that they like having information about the vaccine lot number and company that made the vaccine. They saw it as important in case a vaccine is recalled. However, participants in a few groups noted that banks and credit companies use information such as mother's maiden name as an account identifier, and including this information in the registry might lead to misuse of the information. Others could not see how including the mother's maiden name would be beneficial or necessary.
- **Many participants felt addresses and phone numbers are necessary if parents are to receive vaccine reminders; however, many raised the concern that home address and phone number**

could be a problem depending on who has access. Although they saw the potential benefit of including home addresses and phone numbers, at the same time some participants feared for the safety of themselves or their children, stating that noncustodial ex-spouses, pedophiles, or stalkers could use the registry to find their residence. Some felt that not all the information discussed was necessary. A few others noted that addresses and phone numbers often change, which could defeat the purpose of sending people reminders.

- **Many participants saw including a Social Security number as putting them at risk for being victims of fraud and invasion of personal privacy; yet, a large number of participants expressed little apprehension about supplying Social Security numbers.** Of these participants, some reasoned that the Social Security number is a practical piece of information that is widely used for identification and is given out on a regular basis to other people and organizations. Those who were concerned were worried about who can access the registry.
- **Most participants perceived little problem with the possibility of including health care enrollment numbers.** Several participants suggested that questions about enrollment in WIC, Medicaid, or other health-related systems are routine when a child visits a clinic or hospital, or when the child enrolls in school or Head Start programs. They did not see a problem with providing this information to an immunization registry, and some thought it would accelerate access to the information and reduce paperwork. Only the Korean participants were consistently opposed to the idea of including health care enrollment numbers because of the shame they would feel if it were known that they were recipients of such aid programs.
- **The majority of American Indian participants did not strongly oppose the inclusion of tribal numbers, though few saw the potential benefit.** Participants in the higher educated groups expressed the greatest concern because they felt the tribal number is private information or that the information could be used to single out American Indians. A few noted that tribal numbers are not necessarily unique, and someone in a different tribe might have their same number.
- **Overwhelmingly, parents, health care providers, hospitals/emergency rooms, and health clinics/agencies were immediately mentioned as people or groups who should have access.** However, many added the caveat that only health care providers who treat the child directly should have access.

- **Most participants thought schools should have access, albeit limited.** Allowing access only to immunization information and authorizing access to only certain school personnel, such as the school nurse, were suggested as limits.
- **Some participants supported the idea of researchers having limited access to the registry because of the potential for increasing overall immunization rates, but others could not understand why researchers would want to look at the database at all or were distrustful of research in general.** Some participants in the American Indian groups and the African American groups felt that research results about low immunization rates among minority populations could be used to discriminate against them. In two of the four African American groups, several participants said they would accept researchers having access if it were for surveillance purposes only.
- **Participants in the lower educated American Indian groups and all of the Hispanic groups were more open to allowing a wider variety of individuals and organizations to have access to the information in the registry.** They saw the registry as serving a dual purpose of providing immunization information as well as information emergency personnel could use to treat the child or to contact parents.
- **Many participants voiced spontaneous opposition to health insurance companies having access to the registry.** The primary reason was the fear that insurers might cancel policies or increase insurance premiums if information in the registry labels a child as a high risk. Others saw no threat because they felt that insurance companies already have access to the information. Marketing companies, employers, people who do not work in the medical field, and the general public were also mentioned as groups that participants did not want to have access.
- **The idea of linking the registry to other health care databases, such as those kept by WIC and Medicaid, received mixed reactions.** For several, this was one of the most difficult issues for them to understand, and they could not easily form an opinion about why they should or should not be linked. Others supported linking the systems because they saw it as a way to improve the health of children by making it more convenient for those organizations to share information. A few who were generally supportive said they could endorse the idea as long as the child's name and address were not included.
- **Many participants immediately noted several drawbacks to a law or policy that allows parents to opt out, but very few indicated they would actually opt out if given the choice.** Although the moderators did not specify how parents would be informed that they have the choice to opt out, participants assumed that opt-out cards would be sent in the mail. They feared the cards could be lost

in the mail, sent to the wrong address, thrown out with junk mail, or lost in a pile of paperwork. Most participants perceived this approach as a loss of some personal control over decisions regarding their own children, but the concern about control was not strong enough to keep them from permitting their children to be enrolled. Others saw the approach as a benefit for children, reasoning that the parents who are least likely to follow the immunization schedule will probably not bother to opt out of the registry. Participants in three of the four Hispanic groups and in both of the American Indian groups in Arizona were most consistently comfortable with the opting-out approach, though issues of parental rights and control still surfaced.

- **Most participants favored a law or policy that requires explicit consent of parents before information enters the registry.** They felt this approach is better, because it gives the parents direct control over information about themselves and preserves their right to make informed decisions about their own children. Yet some participants who preferred the approach also saw the possible risk that children will be excluded from the registry if irresponsible parents do not take the time to read, sign, and return consent forms. When asked directly, the overwhelming majority of participants said they would give consent to include their child's records in the registry, but a few added that any mailed requests for consent should be followed with at least two or three reminders in case the first one gets lost.
- **The majority of participants were least comfortable with a law or policy that requires automatic inclusion of children in a registry.** Participants perceived this approach as taking away their control over the release of personal information and their right to make decisions for their children. A few participants characterized it as “un-American” or “too controlling.” Others stated they liked this approach because it is best for the health of the public. They felt the registry would cover the most children and would be most likely to include those children whose parents do not have them immunized. The Mandarin Chinese and Vietnamese participants strongly favored the automatic approach and felt that the other two approaches required too much paperwork and were a waste of time.
- **Participants consistently named convenience of having immunization information in one place as the main benefit of a registry.** If parents lost their own records or changed doctors, they could retrieve records through the registry. A substantial number of participants felt as though the registration process for day care programs and schools would be much easier and faster if the schools were able to access the children's immunization data immediately from the registry. Another commonly mentioned benefit was the decreased chance of a child receiving duplicate vaccines. From a public health perspective, several parents felt the registry would help children whose parents would not otherwise have them immunized. In addition, many participants felt that including the vaccine lot

number and the name of the company that made the vaccine would benefit parents whose child had received a recalled vaccine.

- **Participants most commonly named the possibility of a breach in confidentiality and privacy as the issue about which they were most concerned.** Most participants had questions about who would have access, especially if their address, phone number, and Social Security number were included in a registry. Other concerns were inaccuracy of information and the amount of money needed to support the registry. Several participants mentioned that they were concerned about health insurance companies getting access and possibly denying coverage to those not adequately immunized. A few mentioned their worries about non-custodial parents getting access to their address and phone number. In some of the non-Hispanic white and African American groups, participants expressed concerns about employers obtaining access and using the information to discriminate against them and their children. In the higher educated American Indian group in Tulsa, there was some concern that the registry could become a means to segregate some populations.
- **Participants expressed mixed reactions about law enforcement personnel having access.** Many did not understand why law enforcement officials would need the information, while others felt neutral to positive about such access.
- **Participants did express some concern about being denied entry to school or a day care program if the schools and day care programs had direct access to the registry issue, but most of these participants said they immunized their children and that they would not have to worry about it.** They did mention the benefit of having children who are not immunized banned from school or day care. They felt that keeping sick or infected children out of school would help keep their own children healthy.
- **Most participants said that their doctor's opinion would be a factor in deciding whether or not to participate in the registry.** Of these people, several suggested that while they would consider their doctor's opinion, it would be only one source of information, and that other opinions would be needed before they made a final decision. Some indicated that a doctor's opinion would not influence them at all. In three of the four Hispanic groups, the majority of participants said their doctor's opinion would influence their decision little if at all.
- **Common suggestions the participants had for the people working on immunization registries were concentrated on the importance of accuracy, frequent updating, allowing only authorized users to have access, and respecting the rights of parents to decide if they would like to participate.** Many

also expressed their desire to know exactly what information was going to be listed and who would have access prior to giving or not giving their permission to have their child's records included. Other suggestions included "please include allergic reactions" and "hard copies should be provided to parents."

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SECTION 1. INTRODUCTION

1.1 Background

In spite of record high immunization levels and the virtual absence of many vaccine-preventable diseases in the United States, reaching and sustaining the Year 2000 objective of 90 percent of 2-year-olds being up to date for all recommended immunizations is not guaranteed. Data from the 1996 National Immunization Survey showed that only 78 percent of 2-year-old children had received all of their immunizations. In response to that finding President Clinton directed Donna Shalala, the Secretary of Health and Human Services, to work with the states on implementing immunization registries that will assist providers and parents with the immunization process and, therefore, increase the number immunized children.

The National Immunization Program (NIP) at the Centers for Disease Control and Prevention (CDC) is working with the National Vaccine Advisory Committee (NVAC) to develop a immunization registry plan of action for the nation. This effort has included (1) holding public meetings with registry partners to establish agreement on issues, develop a work plan and timeline, and identify necessary resources; and (2) sponsoring a series of focus groups with parents of young children to obtain their feedback on issues such as access to the registry, what a registry can do, the content of the registry, and how the immunization records get into the registry.

1.2 Purpose of the Study

The primary goal of this project was to gather feedback from parents on how they feel about the concept of immunization registries. To this end, NIP contracted with Westat, an independent research firm, to conduct a focus group study designed to obtain the following information from the participants:

- Reasons why and why not to have a child immunized;
- Reactions to things a registry can do;
- Reactions to the content of the registry;
- Opinions about who should and should not have access to the information in the registry;
- Reactions to the primary ways that a child's immunization record can get into the registry; and

- Perceptions of the most important overall benefits and risks of an immunization registry.

SECTION 2. METHOD

2.1 Overview of Focus Group Research

A focus group discussion is a qualitative research method that provides a flexible tool for exploring issues such as participants' awareness, behaviors, opinions, beliefs, motivations, and experiences related to a particular topic. In a typical focus group, a moderator facilitates an interactive discussion among 8 to 10 participants as they talk about selected topics relevant to the research effort. The moderator ensures that the group covers selected topics, that all group participants are heard, and that potentially valuable conversational tangents are explored. Focus groups yield a wealth of information about how participants view a particular topic, what language and tone they select to express that view, and how they influence each other's opinions and comments.

The focus group method should never be viewed as a replacement or substitute for more quantitative methods such as random sample surveys or controlled experiments. Instead, focus group data *complement* other research findings. Focus groups generate more indepth and sometimes unexpected information than can be learned using other methods. Focus groups should be used, for example, when insights are needed into *why* people behave or think as they do. Also, focus group research is especially appropriate when flexibility is needed to pursue the issues, reasons, behaviors, and concerns that people raise as they respond.

While focus groups can provide very rich data, the results are *not* statistically representative in the way that data from a probability survey are, because sample sizes are relatively small and the participants in a focus group are drawn from a convenience, or quota, sample. Rather than being representative, focus group participants reflect selected characteristics of a given population, which enables this research tool to yield *descriptive* but not *definitive* data. Focus groups are purposely structured so that participants (and, if possible, the moderator) all share some points of similarity relevant to the research effort. For example, they may all be the same gender, all recently have had a child immunized, or all have the same ethnic heritage. Participants who share some common experiences or characteristics are likely to be better able to offer comments during discussion that are related to those criteria. Additionally, having some obvious common ground helps participants feel more comfortable with one another, thereby, encouraging more open discussion.

The written summary of a set of focus groups contains a synthesis of the results wherein several groups are analyzed collectively, general themes and patterns are identified, and any contrasts in

responses from group to group are discussed. Researchers analyzing focus group data seek points of convergence or themes among the groups and may sometimes also note a few surprising or insightful comments offered by single participants that do not necessarily fit into a larger theme. Careful review of transcripts and audiotapes of groups is the most effective means of ensuring that focus group data are accurately interpreted and reported.

2.2 Focus Group Sites and Schedule

Twenty groups plus a pilot group were held during an 8-week period in eight different locations: Rockville, Maryland; Ankeny, Iowa; Baltimore, Maryland; Tucson, Arizona; Tulsa, Oklahoma; Portland, Oregon; Pasadena, California; and Miami, Florida. The Westat task leader, Dr. Tim Edgar, attended all of the groups. At least one Westat research assistant, either Karen Fowler or Kathy Sharp, also was present at each group. Along with the staff from Westat, Judith LeComb from NIP attended each of the groups except for the two conducted in Portland. Dr. Sheree Williams from NIP attended the pilot and all the groups in Ankeny and Tulsa. She also was present for the Hispanic groups in Tucson. In Tucson, K.C. Edwards and Ellen Wild from All Kids Count and J.P. Passino from the U.S. Department of Agriculture were also in attendance. In Portland, Brian Willis, a CDC employee on detail at the Oregon Department of Health, and Karen Burrell and Stacey Shubert from the Oregon Department of Health attended. Katy Turner from NIP attended all of the Asian/Pacific Islander groups in Pasadena, and Sally Foong from the Los Angeles County Immunization Program attended the Vietnamese and Korean groups. In Miami, Alton Reddick, Gail Horlick, and Katy Turner from CDC attended each of the groups, as did Kris Sarlass from All Kids Count.

The selection of locations was based on a plan that allowed for geographic variation and provided sites in which targeted ethnic groups were accessible. For example, Tucson and Tulsa were selected because the relatively high proportion of American Indians in those areas made recruiting groups possible there. Appendix A contains a map showing the sites for the focus groups.

2.3 Participants' Characteristics

In total, 203 individuals participated in the 20 groups and the pilot. The majority of the groups had eight or nine participants, an ideal focus group size. Prior to being invited to participate in these focus groups, potential participants were asked several screening questions to ensure that those persons who attended the groups shared relevant characteristics. The screening criteria were developed to help ensure that participants would feel comfortable in the groups and be able to give knowledgeable input into the discussion of child immunization. Table 1 depicts the characteristics of each group.

Table 1. Characteristics of focus group participants

Location	Ethnicity	Gender	Education Level*	Non-English language
Rockville, MD (pilot)				
	Non-Hispanic white	men(4) & women(5)	higher	
Ankeny, IA				
	Non-Hispanic white	men(1) & women(5)	lower	
	Non-Hispanic white	men(1) & women(6)	higher	
Baltimore, MD				
	African American	men(2) & women(6)	lower	
	African American	men(2) & women(7)	higher	
	Non-Hispanic white	men(3) & women(6)	higher	
Tucson, AZ				
	Hispanic	women(10)	lower	Spanish
	Hispanic	men(2) & women(7)	higher	
	American Indian	men(1) & women(9)	lower	
	American Indian	men(2) & women(6)	higher	
Tulsa, OK				
	American Indian	men(1) & women(8)	lower	
	American Indian	men(2) & women(7)	higher	
Portland, OR				
	Non-Hispanic white	men(2) & women(6)	lower	
	African American	men(4) & women(4)	lower	
Pasadena, CA				
	Cantonese Chinese	men(2) & women(7)	lower	Cantonese
	Mandarin Chinese	men(3) & women(6)	higher	
	Vietnamese	men(4) & women(6)	lower	Vietnamese
	Korean	men(4) & women(5)	higher	
Miami, FL				
	Hispanic	men(4) & women(5)	lower	Spanish
	Hispanic	men(4) & women(5)	higher	
	African American	men(4) & women(5)	higher	

2.3.1 Parental, Educational, and Gender Characteristics of Groups

All participants were the parent or guardian of a child under the age of 6 and said they were involved in making decisions about the health care of children living in the home. Recruiters were asked to

* Lower educated participants were defined as those who had no more than a high school diploma or GED equivalent. There was no minimum education requirement for these groups. The higher educated participants were defined as those who had at least some post secondary education but did not necessarily have a college degree. Individuals with technical training coursework or technical training certificates also qualified for these groups.

screen education level and to stratify the groups by higher and lower education levels. The lower educated groups consisted of participants with a high school diploma or GED or less; the higher educated groups consisted of participants with some post secondary education but not necessarily a college degree. Individuals with technical training coursework or technical training certificates also qualified for the higher education groups.

Often, separate focus groups are held with men and women. In some cases, persons of one gender may feel reluctant to speak openly in front of the other. For example, conventional wisdom dictates holding separate groups with men and women when discussing potentially personal topics such as sexuality. Based on consultation with cultural experts and past experience, the research team and NIP saw no compelling reason to split groups by gender for this study. The recruiters were told to try to recruit a mix of men and women, but strict quotas were not followed. As Table 1 shows, there were more women than men in most of the groups.

2.3.2 Ethnicity

To provide culturally diverse perspectives on the issues and to create a comfortable environment for interaction, researchers recruited groups that were homogeneous with respect to ethnicity. The major ethnic groups included in the study were: Hispanic, American Indian, African American, Asian/Pacific Islander, and non-Hispanic white. During the recruiting process, Hispanic and Asian/Pacific Islander participants who qualified for higher educated groups were told that the groups would be conducted in English, and those participants who qualified for the lower educated groups were told that the group would be conducted in their native language. The two Asian/Pacific Islander groups conducted in English were with individuals who are Cantonese Chinese and Korean. The Mandarin Chinese and Vietnamese groups were conducted in-language. Telephone calls placed to potential participants were conducted in the languages that would be used in the groups. Recruiters followed up with a question about fluency to be certain that the individual would be able to communicate clearly and contribute to the group discussion.

2.4 Logistics of Groups

A variety of planning issues needed to be addressed before and during the series of groups. Several of the most relevant issues such as recruiting, incentives, audio-and videotaping, and services provided to participants are summarized below.

2.4.1 Recruiting and Incentives

Recruiting was conducted by telephone by employees of professional focus group facilities for all of the groups. Whenever possible, the facilities recruited two to seven more participants more than could be comfortably seated in each session to compensate for possible last-minute cancellations. All participants received a \$50 cash incentive payment and either a deli-style dinner or light refreshments, depending on the time the group met. Those who were invited and arrived at the facility, but did not participate in a group due to overrecruiting, received the food and incentive payment they had been promised. In all cases, the overrecruiting situation was explained to waiting participants, and volunteers who were willing not to participate were excused.

In addition to the inclusion criteria discussed in Section 2.3, there also were a few exclusion criteria. Individuals were screened out if they had participated in a focus group within the past year, if they worked in either the social science or market research fields, or if they or member of their immediate families were health care professionals (see Appendix B for the English version of the screener).

2.4.2 Length of Groups

Each group was allotted a total of 2 hours, but the discussion segment for most groups did not last that long. The extra time allowed for participants to ask additional questions and time for the research team to quickly debrief on the discussion that had just concluded. This proved to be beneficial when a second group was scheduled to immediately follow the first.

2.4.3 Facilities Hosting Groups: Audio-and Videotaping and Interpretation

All of the groups were audiotaped, and the groups held in Portland were videotaped so that NIP staff who could not travel could still view the groups at a later date. Participants were always told about the tapings at the beginning of the discussion. The facilities were equipped with the standard, unobtrusively placed recording devices. Observers were seated behind a one-way mirror and participants were informed that observers were present in an adjacent room. For the four groups not conducted in English, bilingual interpreters were present. The interpreters listened to the groups through a headset and then immediately interpreted what was being said for the English-speaking observers.

2.5 Focus Group Moderators

Just as participants in each group were of the same ethnicity as one another, the moderator for each group was also of that ethnicity. All seven of the moderators who assisted with this study have extensive group facilitation experience. The male moderator for the four groups conducted with Hispanic participants is a bilingual native of Mexico. An African American female conducted all four of the African American groups. A white female moderator conducted the groups with non-Hispanic white participants. The four American Indian groups were conducted with an American Indian female who is a member of the Choctaw Nation. Both of the Chinese (Cantonese and Mandarin) groups were conducted by a woman who is a native of China. A woman who is originally from Vietnam conducted the Vietnamese group, and the Korean moderator is a woman who grew up in Korea.

2.6 Moderators' Discussion Guide

Westat developed the moderators' discussion guide after receiving an initial outline from NIP and tested it with the pilot group in Rockville. Changes to the guide that resulted from the pilot included providing more factual background information about registries, reordering the sequence of questions, rewording some questions, deleting some questions, and adding some questions. The English and Spanish versions of the guide can be found in Appendix C.

2.6.1 Discussion Guide Introduction

Important points covered at the outset included welcoming participants and thanking them for their time and willingness to share their opinions; explaining what a focus group is, the process, and ground rules for discussion; and disclosing that there are recording devices placed throughout the room and observers in an adjacent room. Participants were assured that everything discussed during the group would remain confidential and that their names would not be disclosed to anyone other than the research team. To begin, participants were asked to introduce themselves by first name only and to tell their childrens' ages and how they spend their time with their children.

For these discussions, participants had their status as parents or legal guardians and their experiences with making health-related decisions for their children as points of similarity that facilitated openness. The moderator highlighted these points of similarities at the outset of each discussion and also watched for those who seemed hesitant to speak and sought their input.

2.6.2 Topical Discussion

The topics covered by the moderators' guide appear in Exhibit 1. The structured approach used for the guide followed a step-by-step order in which each topic was discussed in a sequence designated by the guide. This approach was used primarily as a way to keep all the participants focused on the topic at hand and to help participants digest the large amount of information being presented. If a participant brought up a topic or question relevant to another section that had not yet been covered, the moderator noted the comment and asked the participant to hold the thought until the topic was covered later during the discussion.

Exhibit 1. Moderators' guide discussion topics

Prevention and Immunization - Discussion of what diseases parents worry about for their children, ways to keep children from getting the kinds of diseases mentioned, reasons why some people get their children immunized and reasons why others do not, and how parents know it is time for their child to get a vaccination.

Background Information about Immunization Registries - Discussion of what an immunization registry is, what an immunization registry can do, and participants' awareness of immunization registries.

Content of the Registries - Discussion exploring participant's reactions to the types of information listed in a registry and the inclusion of additional information (home telephone number, parent and child Social Security numbers, and WIC, Medicaid, and/or tribal numbers).

Access to the Registries - Discussion of who participants feel should have access and who should not have access and how participants feel about the registry being linked to other systems that contain information about health.

Consent and Inclusion - Discussion of participants' feelings toward the three primary approaches states take to include information in a registry, including the disadvantages and advantages of each option.

Wrap Up of Final Thoughts – Wrap-up discussion of participants' perceptions of the most important benefits and risks about immunization registries, and the influence of health care providers' opinion of immunization registries.

2.6.3 Handouts Used During Groups

Due to the large amount of specific information being discussed and the need to keep the discussions under 2 hours, two handouts were created to aid with discussion topics. Information gleaned from the pilot suggested that handouts would be most useful when discussing what a registry can do and

the content of registries. Both handouts were read aloud by the moderator after copies were distributed to all participants. Participants were able to keep the handouts in front of them and refer to them during the discussion of each particular topic. Upon concluding discussion about the particular topic, the moderator collected the handouts.

The first handout listed five things that a registry can do (e.g., if a family moves, the registry can transfer a child's records to a new doctor) and the second handout listed the content of the registries (e.g., type of vaccine, lot number of vaccine). English, Spanish, Cantonese, and Vietnamese versions of the handouts were developed (see Appendix D for all four versions). The handouts were one page each, measuring 8½"x11" and printed on colored paper. After the first handout was distributed, the moderator asked participants for their initial reactions to the items listed on the handout, any concerns they had, any additional questions they had, and whether or not anyone had heard of immunization registries before. After the second handout was distributed, the moderator again asked participants for their initial reactions as well as what listed information participants were most and least comfortable with including in a registry. The participants were also asked about their feelings towards the inclusion of their home address and telephone number; their own or their child's Social Security, WIC, or Medicaid numbers; and tribal numbers for the groups conducted with American Indians.

2.6.4 Discussion Guide Closing

At the end of the discussion, the moderator asked the participants to write down on the pads of paper in front of them one thing they would like to say to the people who are working on the registries. The moderator then excused him or herself briefly and checked with observers to make sure that they had no outstanding questions to ask the group in the final minutes. Upon the moderator's return, participants were asked to read off the comments they had noted on their pads of paper and were given an opportunity to make any final comments. The moderator then thanked participants for their time and gave them information about obtaining their incentive money following the group.

2.7 Data Analysis

As with all qualitative research, the value of focus group findings is especially dependent on researchers examining results systematically. A wide-reaching, multiple-group study like this one produces a large quantity of data, preserved in transcripts, audiotapes, and researcher's notes. The strength of this research method -- detailed discussion that can touch on or delve into myriad topics -- results in data containing very strong clear messages as well as finer, less readily observed nuances. For example, a group of participants may agree on an issue, but they do so for different (and important) reasons and each

does so to a greater or lesser degree. To analyze the findings for this focus group study, the research team used data immersion.

Data immersion is a process based on that recommended by Krueger (1988). In short, Krueger notes that the process for analyzing results must be systematic and verifiable. He recommends processing each group briefly at its conclusion, then developing a total picture of all the groups, and finally considering particular groups and responses to specific questions. This process was carried out by thoroughly reviewing transcripts, moderator topline summaries, and notes for the purpose of identifying key themes and findings. (See Appendix E for the moderators' topline summaries for each group.) All transcripts were reviewed in detail by the Westat research team and then scrutinized for themes and important issues that are discussed in this report.

Reference

Krueger, R.A. (1988). *Focus groups: A practical guide for applied research*. Beverly Hills, CA: Sage.

SECTION 3. FINDINGS

3.1 Prevention and Immunization

As a warm-up activity to facilitate discussion on the topic of immunizations, the moderator guided the participants through a discussion on what diseases parents were concerned about their children getting. The reasons why some parents decide not to immunize their children and others decide to do so were also discussed. The moderator began the discussion by stating that most parents choose to follow the immunization schedule, but some parents have personal reasons for not following it. The moderator emphasized the importance of everyone's opinions and thoughts and encouraged all participants to speak freely. No one in any of the groups indicated that his or her children were not immunized. The discussions revealed that the participants generally expressed similar worries about diseases and illness and mentioned similar reasons for having or not having children immunized.

3.1.1 Diseases Parents Worry About

No one disease seemed to be of major concern to these focus group participants, yet several diseases and conditions were mentioned in almost every group. Several participants stated that they are more concerned about diseases or conditions for which there are no vaccines, such as spinal meningitis, asthma, AIDS, and cancer. Other commonly named diseases and conditions included hepatitis, tuberculosis, chicken pox, and pneumonia, and leukemia, measles, polio, and whooping cough were mentioned to varying degrees. Participants in the African American groups said they were concerned about sickle-cell disease. There were only a few references to lead or food poisoning, such as caused by *E. coli*.

Stuff like pneumonia [be]cause my dad had it and he was always worried about me when I was growing up. (Mandarin Chinese higher education, Pasadena)

Well, something that is life threatening. Like cancer you know. It's just something that's very eerie listening to it. (Cantonese Chinese lower education, Pasadena)

Cancer on both sides of my family and my husband's side too. That's a big scare. (American Indian lower education, Tulsa)

Hepatitis is something that seems to go around a lot with restaurants and stuff. (American Indian higher education, Tulsa)

Respiratory diseases like tuberculosis. I worry a lot about that because [my child] has lots of allergies. (Hispanic lower education, Miami)

The first one is asthma because I have personal experience with it myself. (African American higher education, Baltimore)

A lot of childhood diseases are coming back. Chicken pox, measles. (African American lower education, Baltimore)

3.1.2 Reasons to Immunize

The most frequently mentioned reasons to immunize offered by participants were "schools or day care require them" and "to prevent disease." Other common stated reasons included to protect one's own child and all other children; it is a parental responsibility; and there is a schedule that the doctor instructs the parent to follow.

To keep [the children] healthy as we can. We can keep them healthy by vaccinating them for mumps and rubella. (American Indian lower education, Tucson)

Participant 1: The reason why I take my kids for their regular immunization[s] is that I don't want my kid to go through the preventable diseases that we can prevent by giving the shot. As much as she may not like it, it's for the better health for her. I think as parents we want to prevent the diseases that we can possibly prevent. I don't know if there's any other reason for it.

Participant 2: The second reason could be to go to school, you need the immunizations to go to school. That puts you on a schedule. (Korean higher education, Pasadena)

Well, mine were born in a clinic, in the hospital so they go to their own pediatrician. The same day that they leave they get their vaccination and they have their schedules. (Hispanic lower education, Miami)

3.1.3 Reasons Not to Immunize

A variety of reasons were mentioned when the moderator asked why some parents do not have their children immunized. Some participants said parents do not know there is a schedule or they do not understand the importance of immunizations. Other reasons mentioned included lack of money, laziness, lives that are too busy, parents who do not care, religious objections, fear of side effects, and concerns that the immunizations will not be effective. In the Vietnamese group, there was concern that newly arriving immigrants may be unaware of the immunization programs available in the United States and, therefore, may fail to immunize their children. Participants in the higher educated Hispanic group in Miami mentioned that some may choose to use home remedies rather than conventional vaccines.

I think mainly they probably forget or have other things in mind rather than to take their children to the doctor. (American Indian higher education, Tucson)

People have religious reasons, there are a lot of different things, not just shots, but they carry that into that. My kids are immunized, but I can respect that other people have different feelings about it. That's the one, I don't hear that they're afraid of the complications more than the fact that they have religious reasons. (Non-Hispanic white lower education, Portland)

Participant: They have their home remedy.

Moderator: Some remedies, some people are very traditional maybe?

Participant: Yes, home remedies. (Hispanic higher education, Miami)

In my family out in California, my half-brother's cousin had his daughter vaccinated and she developed polio from the vaccination. For that reason, my brother did not vaccinate his daughter at all. And she hasn't been vaccinated. (American Indian higher education, Tucson)

Participant: Depending on where they live, access.

Moderator: Access to ?

Participant: Access either to a county health facility or private physician (Non-Hispanic white higher education, Ankeny)

I've had a experience with this. I work in the City schools and so you hear about it in the news every September how many kids in the city aren't immunized and I think a large part of the urban culture is well, it's not a problem now. I don't have to do it and there's a lot of denial going on, and their families, it's not really a value to take care of something like that. That's a real big struggle. It's a big fight with them. You're not going to tell me how to parent. (Non-Hispanic white higher education, Baltimore)

Participant 1: Lack of education.

Participant 2: What they know.

Participant 1: What they know about the disease.

Participant 2: Their pre-conceived conceptions.

Participant 1: I think what sometimes may make a difference is health coverage.

Participant 2: Definitely.

Participant 3: Immunizations are free though.

Participant 1: That's true.

Participant 2: That goes with lack of knowledge. A lot of people don't know that it's free. They think you got to pay for it. (African American higher education, Baltimore)

Because they live[d] in Vietnam. They came over here and they don't know [about immunizations]. (Vietnamese lower education, Pasadena)

3.1.4 How Parents Know It Is Time for Immunizations

Most respondents said they receive an immunization card and a schedule from the doctor or hospital when their child is born, and they follow that. Others stated that the school will call them to

remind them, the clinic will send a reminder card, or they will see/hear informational campaigns on radio and television. A few said that they just know when it is time, and it is part of being a parent.

They tell you, believe me, the doctors and, they give you a little card and they'll tell you when they're born that you have to bring them back in a month, after 2 months, after 4, after 6, and after a year. (Hispanic lower education, Miami)

Sometimes the paper will announce you know publicly what kind of, something seasonal perhaps, your flu shots and things like that. So once we find out we can go. (Cantonese Chinese lower education, Pasadena)

It's like a natural thing, it's embedded in the back of your mind. When it gets close to that time it comes into focus and it pops up, so you know it's time to do it. (African American higher education, Miami)

Some physicians do just like the dentists do, what they'll do is they'll send a reminder out. They'll address it to the child because they used to send mail to the parent and the parent reads it and it is supposed to be for the child. (African American higher education, Miami)

I registered my grandson. I had to go get records. Before school starts they tell you if your kids have all their shot and that. (American Indian higher education, Tucson)

Well the day care centers offer too, at break points, give the parent a note of such and such a date unless you provide proof of the next vaccination, your kid can't come back. That's how some of my friends figured it out. (Non-Hispanic white higher education, Baltimore)

With my first I did [keep a chart] and then I just learned certain months, every three months as a matter of fact. (African American higher education, Baltimore)

Several participants mentioned they carry their child's immunization card with them at all times. They commented on how important it is to have the card accessible in case of an emergency. Others said they knew exactly where the card was located at home. The minority who said they have a hard time keeping track rely on the doctor or school to send them a reminder notice.

I carry my children's shot record books around with me. They're in my pocketbook now cause to me I never know, I may have to go somewhere and to me it's like identification. (African American lower education, Baltimore)

Participant 1: We had the cards duplicated. I carry these and if my purse is ever stolen, all the records have been photocopied and put in each one of our children's files.

Participant 2: I have a hard time keeping track. Just recently, I had to go and get my oldest son's record updated so I went to the pediatrician. We switched doctors once. I don't have the card in my purse. I'm not organized.

So I relied totally on the doctor to keep the records and if he didn't keep them, I would not have [the information]. (Non-Hispanic white higher education, Ankeny)

3.1.5 Ways to Make Keeping Track of Immunizations Easier

When participants were queried about what would make it easier to keep track of their child's immunizations, responses included obtaining a printout when you leave the doctor's office of the immunizations your child received, including the age of the child in the immunization booklet, keeping two separate booklets (one for infants and one for school-age children), having a durable card that could be punched or stamped each time a child receives a particular vaccination instead of filling in blanks manually, and seeing more public announcements on television. Several participants felt strongly that it is their duty and responsibility to keep track.

I take it personally upon myself to be aware of what is required for my children. (Non-Hispanic white lower education, Portland)

Participant 1: I think it would be nice if they (the doctor's office) could photocopy their page and give you a copy, but they can't, they have to handwrite everything over to another sheet if you want a copy of it.

Moderator: So it could be done but they don't do it?

Participant 1: Right, cause they said they're not allowed to. Some legal thing.

Moderator: For copying medical records. Anybody think of something else?

Participant 2: They could probably do like a little hard card that they could punch that you could keep in your wallet.

Moderator: Sort of pre-printed and when you get that vaccine you just punch it.

Participant 3: You need the dates of the vaccine.

Participant 2: Or they can stamp it, it could be something like a stamp. (Non-Hispanic white higher education, Baltimore)

Participant 1: Since [immunizations] are State mandated, it would be nice if there was a central number you could call for everything that's called in. With my two younger [children] we were trying to figure out what they had for health care. It was like going to Broad Lawns, going to one pediatrician they had at a time. Just like putting pieces of a puzzle together to figure out what they had and what they hadn't and it would have been so nice if there was one number you could call, OK, this is it.

Participant 2: I agree, if there was some sort of [number]. If the physicians were held accountable for reporting every time they gave immunizations to a central number and you could access that number. (Non-Hispanic white higher education, Ankeny)

Participant 1: We have Kaiser and they have started every time you take a child in, they give you a printout along with whatever else of their shots. Every

time I take a kid [to the doctor] that child's immunizations are on the piece of paper you come out of there with.

Moderator: *So you have an updated record all the time that they provide. Is there anything else that you can think of that would make it easier?*

Participant 2: *I think it's a great idea of the printout. I think that's wonderful. (Non-Hispanic white lower education, Portland)*

I think public announcements on television. And not just say, 'Go vaccinate your kid.' We all know about it. It is two months, four months, six months, and all of a sudden it's 12 months and then two or three years and then five. You forget when you're supposed to. (Hispanic higher education, Tucson)

Some participants offered tips to others in the group on how they keep track, such as keeping a filing system and having a memo pad on the refrigerator with written reminders to themselves.

I have a drawer where I have files like for bills and I keep my shot records there. So I suggest they keep some kind of file drawer, organizer. (African American lower education, Portland)

I put it on my calendar. As time goes by, I put the mark down when they're supposed to get it. And you keep track on your calendar. And I keep a book of vaccinations and I put in the month they are supposed to be given. (Hispanic higher education, Tucson)

On the refrigerator I have a large memo pad and I just fill it in, birth date, baby shots, anniversary. (African American higher education, Miami)

3.2 Immunization Registries

The next section of the group discussions focused specifically on the concept of immunization registries. The moderator introduced the subject and read background material about exactly what a registry is. The moderator then distributed the handout listing five things that a registry can do, and participants were asked for their initial reactions. The moderator probed for participants' concerns, questions, and knowledge of registries, and asked if anyone's child was in a registry.

3.2.1 Things a Registry Can Do

After reading through the first handout, most people had a generally positive initial reaction to the idea of an immunization registry. Participants in virtually every group commented that registries sound great and are a good idea. Many expressed their delight with the fact the registry could send out automatic reminder notices. Others thought the benefit of transferring records to a new doctor was a real asset of the system. In addition, several participants liked the idea of the registry producing a printout that they could give the school, a day care program, or a camp for registration purposes.

Participant 1: It's good.

Moderator: Why, from what I said?

Participant 1: It simplifies the process.

Participant 2: We all need it.

Moderator: Why is it something we all need?

*Participant 2: We all forget. Sometimes we cancel an appointment or forget.
(Hispanic higher education, Tucson)*

I think it's all good, but I like [the idea] that if you need it to go to school and if you lose it whatever, you can get it copied. Or misplace it or whatever you do. And then you can transfer your child's immunizations. You won't have to be backtracking and going back and forth and everything. (American Indian higher education, Tucson).

Participant 1: I can't believe they don't have anything like this already.

Participant 2: It would have been nice when I was going to school. I wouldn't have had to re-do some of [the information] because my mother lost some of my records. (Non-Hispanic white lower education, Portland)

I just switched doctors recently and had to go all the way back to my original doctor. They couldn't just fax something. Then they finally did fax it after I complained a lot. It would be more convenient for parents who move around a lot. (African American higher education, Miami)

I think it's very good because I have a friend who had her son to go to school, and she lost her son's [record] so she had to take her son to the health center and get the immunizations all over again cause she lost the book, record. (Korean higher education, Pasadena)

Knowing that this information is somewhere. I mean God forbid your house could burn up or something or you can lose it, fire, hurricane, whatever, at least you know somebody has this information somewhere. You can be moving next week and your doctor wherever they are has access to this information, so a plus would be the possibility somebody else has knowledge of what's going on. (African American lower education, Miami)

Several participants did not see the registry as a substitute for traditional record keeping (e.g., immunization record books). Even some individuals who expressed general support for the registry, called the system a “fail safe,” meaning it is a source of information if parents lose their own records. Participants said they would continue to keep hard copy records to compensate for possible inaccuracies in the registry.

You got an appointment for this one and the doctor can't fit you in and he reschedules you and he forgets. He has another doctor that's in there, who's going to substitute to see your kid, you kind of lose track. To me it is like a fail-safe, it is a back up system where you go to your regular doctor's office. (African American higher education, Baltimore)

For parents that do keep track of the records, they would have a back up in case they lose or misplace or whatever. For the parents who don't, they have someplace they can go get that information. (African American higher education, Baltimore)

Although overall initial reactions were very positive, some people voiced their concerns about issues such as the accuracy and privacy of the data. Participants wanted to know if only the health care professionals who care for their child would have access or if all doctors would be able to view their child's record. Many were also curious about who was entering the data. They expressed the need for someone who takes exceptional care in making sure all data are correct and updated frequently. Some felt the purpose of the registry would be defeated if duplicate vaccines were administered or vaccines were missed due to inaccurate data entry. Several participants also had concerns about the cost.

My initial reaction was 'great' but what exactly does it involve to have this available to us? I'm concerned as anybody about my privacy also. They might want to know a lot of things. (Non-Hispanic white lower education, Portland)

The main question I would need to make sure that my privacy was still kept, you know, regardless of whether it's accessible or not. (African American lower education, Portland)

Participant 1: I think the security of it [concerns me]

Participant 2: That's what I was going to say, even [though] they say nobody has access...

Participant 3: Well, let's say who's going to get the immunization shots [into the system]? Is it going to be the doctor? Is he going to be responsible for contacting the registry? Are they going to be willing to do that and keep it up to date? (Hispanic higher education, Miami)

I'm kind of nervous about the data that's been collected and how that data will be used. Maybe it will be used against you. Maybe health services will look at all that data and do a query on all bad parents who didn't have their children immunized and they'll go either forcefully and take them away from their family. I'm worried about any governmental centralized databases. (Korean higher education, Pasadena)

If something happened. My daughter got her shots yesterday and two days from now she got hurt, well, has she been vaccinated for this? How soon is that available cause I wouldn't carry vaccination cards with me. If we're out at the park and she fell down and something happened, I know I had this done and I think it was this. You're panicked at the time, how accurate are the records going to be kept? Is there going to be like a check in counter, the next day...within 24 hours it's updated nationwide? How soon are these available if something does happen? (American Indian lower education, Tulsa)

Participant 1: How's it going to be updated? Who's going to have access to this information to update it properly? They might leave off the last R because there were no more characters in that line and they don't think that R is needed.

Moderator: So you want people to be trained is what you are telling me?
Participant 1: Exactly.
Participant 2: And you don't want them working for \$4 an hour putting that on, not that labor pool that's for sure.
Participant 1: Are they just going to be putting in medical information or are they going to be inputting all my information? Is the responsibility going to rely on the doctor? Again, there's just a very slim, slim margin for error. (African American lower education, Portland)

Non-Hispanic white participants in Iowa had the most negative initial reactions to the idea of a registry. At least one participant in both of these groups immediately voiced his or her concern that the registry is a form of “government control.” A few also stated that the information in the registry is duplicative of the information they already keep as responsible parents. However, the overall initial reaction of both of these groups toward the registry tended to be neutral to positive rather than negative.

There are some parents who don't get their children immunized. The State can come back on these parents and say why don't you get your son or daughter immunized? Some people may not be able to afford it and that's really not the State's, that's not what they are there for. If they're going to offer to pay for it fine, but if they have a national registry, it's just another way to control my opinion. That's what we pay our doctors for. (Non-Hispanic white lower education, Ankeny)

Will the State recognize those people who do not want to have their children vaccinated for various reasons? I could see this becoming a compulsory thing. Will they acknowledge it for religious reasons? If it's going to be just a matter of collection of information, here it is, that's one thing, but if it becomes a mandatory thing and your abdicating some of your parental ... I mean I can see where it is that you're not looking after the welfare of your children, and now it's been turned over to Social Services or something. (Non-Hispanic white higher education, Ankeny)

3.2.1.1 Benefits of Immunization Registries

After the moderators elicited initial reactions, they probed for more detail about perceived benefits. Avoiding duplicate vaccines, receiving vaccine reminder notices, and the sharing of data were common benefits mentioned. Some respondents stated that registries would lessen the amount of paperwork and phone calls for doctors, schools, day care programs, hospitals, and parents. Others mentioned the benefit of having all records in one place, especially for parents with several children.

Well, it will never be misplaced; the record will never be misplaced. (Cantonese Chinese lower education, Pasadena)

Having 3 children, those little things you don't think about it. Every year September comes around and 2 kids bring this bunch of paper and I always look for health information cause I don't have the yellow card so I have to call the doctor's office so it

would really eliminate a lot, not a lot but this little burden off of me. (Korean higher education, Pasadena)

Participant 1: That's what I was going to say happened to my sister. She didn't keep her son's book and he had to get re-inoculated. I don't want to put my son through that.

Participant 2: For a doctor other than your child's pediatrician, they're treating your child and they need that information, they have someplace else to go. If your child's pediatrician isn't available, they have another source for that information. (African American higher education, Baltimore)

Access for doctors; for schools; for any emergency situation. I think that's good for me. (Hispanic higher education, Tucson)

I think it's great I really do. Think of something to make our lives easier. I think that is really cool. It does, it would make our lives a lot easier. Like if you are moving, traveling, you, lose that, you can always get it back. (American Indian lower education, Tulsa)

3.2.1.2 Concerns About Registries

When participants were probed about what concerns they had about registries, access and privacy were key concerns. Other common concerns were the accuracy of information, potential invasion of privacy, computer fraud, and the cost. Many participants wanted to know who would have access, who was entering the data into the system, at what age records are removed, and what registries will cost the taxpayer. In the higher educated American Indian group in Tulsa, there was some concern that the registry could become a means to segregate some populations, and in two each of the four non-Hispanic white and African American groups, participants expressed concerns about others (e.g., employers, health insurance companies) obtaining access and using the information to discriminate against them and their children.

[I am concerned] because in the United States the names are very confusing. You can confuse one name with another because if you have an information pool, you're talking about a lot of names, so you know you can get the address, you can send mail to the wrong address, things like that. Mistakes like that happen all the time. (Cantonese Chinese lower education, Pasadena)

My concern is if it's going to cost some money, you know you're going to have to make payments to it or the government. [Who] is going to take care of that? The public school system? (Hispanic higher education, Miami)

Who can hack into it besides the health care provider and the state and find out things? Add things? Delete things? (Non-Hispanic white lower education, Portland)

I think it's very good in a way parents could be reminded for due shots. The one thing that might concern me is what if the wrong information was inputted and how difficult or

easy it would be to correct mistakes or how often can you go into the information to cross check the inputs that they make? That could be a concern. (Korean higher education, Pasadena)

It could be used against you. We're saying that our ethnic people are not getting their well baby care shots, so let's up their premiums. (African American higher education, Baltimore)

Participant 1: I don't want to give you my child's name that you can pull up his entire history when he's 18.

Participant 2: So then you just give up all the information and when it comes down to the employer he can say well, I see he was treated for AIDS, we can't hire you. (African American lower education, Portland)

Participant 1: I have a question before we go further, does this apply to the Indian Nations only, or does this apply to everybody in America? That's my question.

Moderator: What would concern you? Would it be important to you one way or the other?

Participant 1: Yeah it would be because I would see once again and I see this just recently in the housing programs and stuff the Indian Nations have that you can no longer be on those programs if you don't have CDIB cards and things like that. Once again I see a segregation of the Native American and is that what their intent is?

Participant 2: I'm just checking. I just see it in different things, they're separating us from ... And different things that the Federal Government does for us as a whole or that they promised to our fathers, whatever. They said they'd give us and now I see things moving in a different ... You know maybe a lot of people do see it, but I see it that they're moving us in a different direction and I'm not sure I really like that.

Participant 3: Well I think the [registry] is great but I would question [some things]. I really would because if they can like she says segregate you. I heard something a long time ago. I'm sorry, I'm very opinionated. I don't get --- a chance to talk. I remember there was a man that was in downtown Tulsa who used to go every weekend and he'd stand up on his little box and talk about how the government was immunizing but they really weren't immunizing, they were sterilizing. Has anyone ever heard of that? If they can segregate you by a registry and then who's to say they can't give you a certain batch of medicine or immunizations.

Participant 4: They can still segregate you whether it's for everybody or not cause if you mark on something you know, American Indian or whatever, they can pull up a data base. (American Indian higher education, Tulsa)

3.2.2 Content of the Registries

As the moderator continued the discussion, he or she distributed the second handout, which listed the typical content of registries. The top half of the handout listed four items that are typically

entered in a registry for each child: type of vaccine, date of administration, company name, and lot number. The bottom half of the handout listed four things that *may* be entered into a registry: child's name, child's date of birth, child's gender, and mother's maiden name. Participants followed along on the handout as the moderator read each list to participants. Participants were then queried for their initial reactions to the information on the handout. The information on the top half of the handout raised little concern. The majority of participants mentioned that they like having information about the vaccine lot number and company that made the vaccine. They saw it as important in case a vaccine is recalled. Many participants strongly suggested that allergies should also be recorded in the registry to decrease the likelihood that a child is given a potentially harmful vaccine.

Sometimes there are problems with batches of vaccines so [the registry] might be a good way to pull people up who got what. If there's a problem, they can monitor the people who had gotten that particular lot...So it would be helpful. (Non-Hispanic white higher education, Baltimore)

I think it is a good idea to have the lot number because of the bad batch and you know all the kids that were immunized with that batch and they can be re-immunized with the right batch, I think that's good. (African American higher education, Miami)

Well, good because I think that if the vaccination was not effective, if it had a problem in its manufacturing, you can find out through this. (Hispanic lower education, Miami)

Participant 1: Do you think in the content information they are going to have information on if the child is sensitive to this sort of medicine?

Participant 2: Allergies.

Moderator: Are you talking about adverse reactions?

Participant 1: Yes.

Moderator: You think that should be included, too?

Participant 1: Yeah.

Participant 2: And whoever gave you the shot, what hospital or doctor. (Hispanic lower education, Tucson)

Participant 1: For me this is something new. I mean this is very specific. Every time I get a record I only have what type of vaccine my kid has. The date of vaccine also, but company that made the vaccine or lot number of vaccine, this is something new.

Moderator: Well what do you think?

Participant 1: This is very specific. I mean if they could provide this, this would be really helpful. (Korean higher education, Pasadena)

The information on the bottom half of the handout was generally well accepted, though some people questioned the need for some of the information or wondered if the information could be misused. Many participants felt the information was needed to make a child's record unique to that of other children's. For example, if there are two children with the same name living in close proximity, the birth

date or mother's name could be used to verify the owner of the record. On the other hand, participants in a few groups noted that banks and credit companies use information such as mother's maiden name as an account identifier, and including this information in the registry might lead to misuse of the information. Participants in a few other groups could not see how including the mother's maiden name would be beneficial or necessary. Several participants, primarily in the African American groups, wanted to know why the father's name was not included. To a small extent, individual participants in different groups were not comfortable with or saw no need to include information about birth date or gender. Concerns about birth date and gender suggested fears of computer pedophiles or stalkers.

Moderator: *What is your initial reaction after reading this?*

Participant 1: *Yeah, I think it is OK.*

Participant 2: *I was wondering why they don't put the father's name. (Mandarin Chinese higher education, Pasadena)*

I think it is good. I don't think it's anything that I wouldn't want someone to know. I wouldn't mind my name being on there and my maiden name seems okay to me. (American Indian lower education, Tulsa)

Participant 1: *Why would it just be the mother's name, why isn't the father's name there?*

Participant 2: *Why do they need my child's gender? (African American higher education, Baltimore)*

I don't like the part where it has the mother's full name and maiden name cause there are some things as an adult you have to have. If you call and check on something over the telephone, you usually have to put your Social Security number or if you talk to a customer service representative, to make sure that you're the person that account belongs to, there's like a code and it's usually what is your mother's maiden name and how long would this be kept and who would have access to it? That's the only thing I don't like on there, but the rest I think is good to have on it. (Non-Hispanic white higher education, Baltimore)

I just don't see the point of a maiden name. What does have to do with your kids and their vaccination, you know what I'm saying? (Hispanic higher education, Miami)

3.2.2.1 Reactions to Including Home Address and Phone Number

When the moderators suggested that home address and phone number might also be included, many participants felt uncomfortable with the idea, because they were unsure who would have access. Some participants feared for the safety of themselves or their children, stating that noncustodial ex-spouses, pedophiles, or stalkers could use the registry to find their residence. Some felt that not all the information discussed was necessary. A few others noted that addresses and phone numbers often change, which could defeat the purpose of sending people reminders; however, many participants felt addresses and phone

numbers are necessary if parents are to receive vaccine reminders. Others supported including addresses and phone numbers, because they thought such information could be used to contact parents in case of an emergency, and the information could be used as additional identification to prevent confusing records of children of the same name.

How are they supposed to contact you? I see no way for them to contact me. If something is wrong with this batch of medicine, how are they going to contact me? (African American higher education, Baltimore)

For them to know where I live [is important] so they have more complete information and don't put another address. That person might have the same name, so to avoid confusion that way. I would prefer for them to have an address to communicate with you if needed to, yes. (Hispanic lower education, Tucson)

It's not necessary because you move and your phone number will be changed. You keep your Social Security number that's it. (Mandarin Chinese higher education, Pasadena)

Participant 1: Too much information.

Participant 2: [I'm concerned] because somebody may be up in there trying to stalk me.

Participant 1: They stress that with my child in school because they get on computers and they can't put any type of information, their whole name they can't even put in there, so that's why I am kind of hard on that, because we have some perverts. (African American lower education, Baltimore)

Participant 1: I don't think that is necessary.

Participant 2: It depends on who can get the information. If it's set up where you have to authorize access to that person...

Participant 1: But still, if it goes on the computer system...

Participant 3: Anybody can get it.

Participant 1: There's no guarantee. (Korean higher education, Pasadena)

Participant 1: That would make it worse. To me, it makes it seem like telemarketers or any other people who are already getting into the Internet and using the information for their own needs are going to get access off the computer and use it for their own purposes. Whether it is intentional or unintentional and that really tickles my tummy.

Participant 2: No it's not necessary. You end up moving somewhere else or the kid grows up and moves out of the house. (American Indian higher education, Tucson)

3.2.2.2 Reactions to Including Parent's or Child's Social Security Number

Many participants saw including a Social Security number as putting them at risk for being victims of fraud and invasion of personal privacy. These issues were often tied to concerns about who can access the registry. Some respondents said it is not necessary to have all identifiers on the registry. For

example, if the registry includes the mother's maiden name or address, it is not necessary to also have the Social Security number. Yet, a large number of participants expressed little apprehension about supplying Social Security numbers. Of these participants, some reasoned that the Social Security number is a practical piece of information that is widely used for identification and is given out on a regular basis to other people and organizations.

Social Security [numbers], that's like your ticket to everything if someone gets a hold of it...those numbers can be like a fire bomb going off. You have to be very, very delicate working with people, especially children. (Non-Hispanic white higher education, Baltimore)

Participant 1: Invaded.

Moderator: You would feel invaded?

Participant 1: Yeah because just about anybody that sees it would be able to call up anything they want on it. If it has your address, your telephone number, your Social Security number, they can call up just about anything on the computer about you.

Participant 2: They have everything else anyway.

Participant 3: Social Security number that's the first thing when you go to enroll a child in school anymore. When you claim him on your taxes they got to have ... They're using their Social Security number as much as we're using ours as adults, so what would make any difference?

Moderator: How do you feel about Social Security numbers?

Participant 4: I think it would be OK. It's out there everywhere anyway. (American Indian lower education, Tulsa)

Participant 1: You're missing one impertinent thing. In this day and age you need a Social Security number. You need a notification number.

Participant 2: If you call and say I want to make an appointment for my child and they might give me a name and they're not spelling you name right, they'll ask you for the Social Security number and they punch it in and the child's name comes up. (African American lower education, Baltimore)

Participant 1: It's good to have the Social Security because you might have a child with the same name and they have a different number

Moderator: So it doesn't get things messed up. Any other reasons?

Participant 2: It's real important for me because for information or an emergency, the Social Security number doesn't lie. That's all the information there. You can access a lot of information with a Social Security number. You know with the telephone number you might not be able to get the parents, they might be working.

Participant 3: I am uncomfortable with it. My doctors have the Social Security number of all my children. Well, for example, let's get it out. There's a lot of false Social Security numbers. Mine's being used in California; another person has my son's. There's a lot here in Tucson. Among us there are three other people using our Social Security numbers.

There's a lot of false Social Security numbers. (Hispanic lower education, Tucson)

Participant 1: It's OK because there's not that much difference in the card, but this kind of information would allow people to just follow you? Like I said later, who can go in? If it's really important that it has to have this information, then I will not object. If anybody can have access to it, then I object.

Participant 2: I don't want it in there. For me, I don't want mine to be in there.

Participant 3: I don't know. I'm rather conservative about my own you know. Safety or my confidentiality because you know something that is public and is not involved with this program so another person can access it just for fun and I would like to keep it secret. I'd like to protect that information.

Participant 4: In America, whatever you do or don't do, they know everything about you.

Participant 5: Yeah, the same. Like Medi-Cal, what others have said, all the numbers are in there. (Vietnamese, lower education, Pasadena)

3.2.2.3 Reactions to Including WIC and/or Medicaid Numbers

To conclude the discussion on content, the moderator queried participants about their feelings toward including unique health care enrollment numbers in a registry. Most participants perceived little problem with the possibility. Several participants suggested that questions about enrollment in WIC, Medicaid, or other health-related systems are routine when a child visits a clinic or hospital, or when the child enrolls in school or Head Start programs. They did not see a problem with providing this information to an immunization registry, and some thought it would accelerate access to the information and reduce paperwork. A few felt including the WIC number in the registry is a reasonable idea, because WIC and the immunization registry have the common goal of improving children's health. Only the Korean participants were consistently opposed to the idea of including health care enrollment numbers because of the shame they would feel if it were known that they were recipients of such aid programs.

Why would they need that? You're getting into there already, let's make this a little bigger, let's squeeze this in. Well, what about this too? Okay, here's my life. (American Indian lower education, Tulsa)

I think if I was in one of those programs, it wouldn't bother me. (Non-Hispanic white lower education, Ankeny)

Participant 1: It's fine, it's kind of all the same thing.

Participant 2: When you go to AHCCCS and WIC, they will tell you about immunization anyway.

Participant 3: It helps with paperwork. (Hispanic higher education, Tucson)

Participant 1: What's the purpose?

Participant 2: It may not be a permanent number? Kids are on WIC up until a certain age and when they get off you don't need that information.

Participant 3: I have no problem with it. It's just your generic information. Like you said until the child comes off the program, that's fine.

Moderator: Comfortable, not comfortable with Medicaid numbers?

Participant 4: It's not a permanent record that's there with the child for life like the Social Security number. They will not change that number. (African American higher education, Miami)

Participant: I wouldn't like it.

Moderator: Why is that?

Participant: It's telling everybody I'm poor, I'm getting the help from the government. I think your pride goes so far. You're just hurt enough to get the help from the government. You don't have to tell the whole world on the child's immunization card that your parents are not sufficient to support you with the Medi-Cal, so I wouldn't feel very comfortable. (Korean higher education, Pasadena)

3.2.2.4 Reactions to Including Tribal Numbers

In the focus groups with American Indians, a probe was added that asked how they would feel if tribal numbers were included in the registry. Some participants did not mind including the information, though few felt it would be beneficial. Participants in the higher educated groups felt the tribal number is private information or that the information could be used to single out American Indians. A few noted that tribal numbers are not necessarily unique, and someone in a different tribe might have their same number.

The reason for not having tribal number in there is that the Yaqui's is probably all right because there's very little chance someone will have the same tribal number as the Yaqui's, because they have such long numbers. But my enrollment number from my reservation is xxx. That's my enrollment number, xxx. But I could see in another tribe somebody else could have another xxx. So again you would have duplicate information someplace. I don't think it needs to be on there. It would just add to the confusion. (American Indian higher education, Tucson)

Moderator: You would prefer your clinic number? Your chart number would be your enrollment number?

Participant 1: Yeah.

Participant 2: But then you're singling yourself out.

Participant 1: As an Indian.

Participant 2: That's right.

Participant 1: What if you don't have it. You need a number that everybody's got, that everybody uses.

Participant 2: If you use that to me you're singling yourself out. (American Indian higher education, Tulsa)

3.3 Access

During this part of the discussion, participants were asked for their opinions about whom they felt should have access and should not have access to the registries. The issue of access had been brought up several times earlier in each of the groups, but it was systematically discussed during this part of the groups.

3.3.1 Who Should Have Access

Overwhelmingly, parents, health care providers, hospitals/emergency rooms, and health clinics/agencies were immediately mentioned as people or groups who should have access. However, many added the caveat that only health care providers who treat the child directly should have access. A few participants, when probed by the moderators, felt that only custodial parents should have access.

As long as there are limits as far as the access to the information, as long as they are there, I think it is a good idea because it helps to simplify things not only for the parents but the health care providers. (African American higher education, Baltimore)

Participant 1: Doctors.

Moderator: All doctors?

Participant 1: No. Just the treating doctor for the child.

Participant 2: I think in general all doctors, parents, and guardians. Sometimes you can't go to an appointment for a vaccination or when the child is sick. Sometimes you can't be there and it would be nice if your grandmother or some extended family member could. (Hispanic lower education, Tucson)

Participant 1: Who in the health care provider's office [would have access]? In a hospital there are so many people. I wouldn't want to think that just anybody could go into their computer and pull that up on my kid just because they want to see it.

Participant 2: As far as the receptionist who sits at the front desk, she really wouldn't need to have access to that kind of information. (Non-Hispanic white lower education, Ankeny)

Only [custodial] parents because it could be your ex who would want that information to maybe kidnap them or something like that. (American Indian lower education, Tucson)

In a few of the groups, the moderator had to probe participants for their views about schools having access, yet in the majority of groups, participants spontaneously expressed their opinions about schools early in the discussion. Overall, most participants thought schools should have access, albeit limited. For example, some felt that access about immunization status, but not other medical information

that might be in the registry, would be appropriate. Also, participants felt that only certain school personnel, such as the school nurse, should be authorized to access the registry. Other participants did not see a reason for schools to have access to the registry. They agreed that schools only need to see an immunization record one time — when the child enters school for the first time — and that it is better for the parents to provide that information themselves rather than the school accessing it through a computer.

I don't think the school should be involved. I want them to come to me if they think my child has not had something. (African American higher education, Baltimore)

School administration instead of hassling the parents. [If] they have this list, they can just go in and access it. (Korean higher education, Pasadena)

Participant 1: I don't think they should have access. The only thing they need to know is if the child is up to date and you can give them that information.

Moderator: Do you agree with that?

Participant 2: They should just be able to be given the information. (American Indian higher education, Tucson)

Participant 1: It might be a big help for the schools, instead of tracking down everything, they go right to the computer and get all the information.

Participant 2: I think it is a waste of resources for the school to have the information...there's got to be a better way to do this. You need a trained individual to access it. (Non-Hispanic white higher education, Baltimore)

Participant 1: In my case I think, yes. It's really helped me when the schools had the information. On one occasion, I didn't give them the information. I didn't think it was necessary. My child was allergic to penicillin. I don't know how they got the information, but they found out from the previous school that my son had this allergy to penicillin. I didn't have any indication of allergies and through the other school they were able to find that out and not give it to my son.

Moderator: So what else is important?

Participant 2: When you enroll them you don't have to be looking for the book and taking in your records. They'll already have them in the computer. (Hispanic lower education, Tucson)

Facilitating discussion about researchers obtaining access required some probing on the part of the moderator. Most groups did not mention researchers spontaneously and there were multiple opinions about allowing them access to the database. Those who supported researchers accessing the registry saw potential for increasing overall immunization rates. But some who felt researchers should have access to the registry also included the condition that researchers should not have access to personal identifiers such as names, addresses, and Social Security numbers. Others could not understand why researchers would want to look at the database at all or were distrustful of research in general. In two American Indian

groups and in three of the African American groups, at least one participant felt that research results about low immunization rates among minority populations could be used to discriminate against them. In two of the four African American groups, several participants said they would accept researchers having access if it were for surveillance purposes only.

I, myself, don't believe in research and surveys and all that kind of stuff. I have this idea in my head that we are guinea pigs and a lot of things have happened that enforces my opinion of that, so it would kind of bother me. (American Indian lower education, Tulsa)

Participant: Government should have access to that --- like there is a Center for Disease in Texas or something like that.

Moderator: Centers for Disease Control and Prevention?

Participant: That facility should have access to the database.

Moderator: For what purpose?

Participant: For research purposes and control. (Hispanic higher education, Miami)

Participant 1: Well, they need to know, they want to know if the kids are getting immunizations shots and who's not and how many people are doing it, how many not. How many are being responsible, how many are not? To get on the issue we need to get the children into the doctor to get their immunizations.

Moderator: So you're saying yes?

Participant 1: Yes, it's kind of good because to get like, what I'm trying to say is, when they research and find out who is doing it and who's not, they can see if there's a lot of them who are not, we need to go and help those who need to know where to go or get more information on how their children could be more healthier.

Moderator: There's no problem if it's a statistical situation is what you're saying?

Participant 1: Right. (African American lower education, Portland)

If some researcher wants to get my records, well, they could ask me and tell me why or something. I'd probably give them permission, but I don't want them just rooting around without me knowing about it. (Non-Hispanic white lower education, Portland)

Moderator: How about researchers, health researchers? Do you think they should have access to this information?

Participant 1: It depends.

Participant 2: No. It's OK, but what I don't like is some research, cause I like to do some research for myself, but I don't want people to keep calling me, say every 10 minutes, 20 minutes, so I really don't want to.

Moderator: You're afraid they might call you and bother you?

Participant 1: I don't know who those researchers are and depending on like do they work for an insurance company?

Moderator: This would be people like health researchers, further the study of a particular vaccine. Health researchers not insurance.

- Participant 1:** *Yeah, that would be OK. Like some agency, non-profit organization, that would be OK.*
- Participant 2** *That's OK, but what I'm saying is don't keep calling. Some people do keep calling you. (Mandarin Chinese higher education, Pasadena)*

Participants in the lower educated American Indian and all of the Hispanic groups were more open to allowing a wider variety of individuals and organizations to have access to the information in the registry. They saw the registry as serving a dual purpose of providing immunization information as well as information emergency personnel could use to treat the child or to contact parents. Participants in these groups named hospital emergency rooms, fire departments, 911 personnel, poison control personnel, and to a lesser extent, law enforcement personnel as those who they would not mind having access to the database.

- Moderator:** *Who else should have access?*
- Participant 1:** *There should be like an alternate person in an emergency. If me and my husband were to die in a car wreck.*
- Participant 2:** *In case of an emergency, yeah.*
- Participant 3:** *Law enforcement as far as that goes cause I mean what if they can't track down who you have in case of emergency and they're going we need this medical information?*
- Moderator:** *Who else?*
- Participant 1:** *We can't shut out the government of course.*
- Moderator:** *So you're saying the government should have access?*
- Participant 1:** *They're going to anyway.*
- Participant 2:** *It's not that we're saying they should.*
- Participant 3:** *If they want it, they can have it. (American Indian lower education, Tulsa)*
- Moderator:** *Who else should have access?*
- Participant:** *Emergency people. (Hispanic lower education, Tucson)*

3.3.2 Who Should Not Have Access

Many participants voiced spontaneous opposition to health insurance companies having access to the registry. The primary reason was the fear that insurers might cancel policies or increase insurance premiums if information in the registry labels a child as a high risk. However, in some groups health insurance companies were never mentioned until the moderator specifically asked. In these cases, participants often had no opinion as to whether health insurance companies should have access to the registry or not. Many saw no threat because they felt that insurance companies already have access to the information.

- Participant:** *It seems like it would make life easier for everybody if they [health insurance companies] had access.*
- Moderator:** *How could it, they make life easier?*

- Participant:** *Well, if they've got access to that information, I can't think of a situation but somehow they can find out whether the child had it or not or if it has anything to do with billing, they can, they can probably solve that type of problem, you know among themselves, the providers. (Hispanic higher education, Miami)*
- Participant:** *If they know your past history and stuff, it might be harder for you to get insurance. (American Indian lower education, Tucson)*
- Participant 1:** *No, information could be used against you. 'We're seeing that our ethnic people are not getting their well baby shots, so let's up the premiums.'*
- Participant 2:** *It could be a glitch, 'oh, your child's not getting well baby care, guess what, we can drop him off your health care.' (African American higher education, Baltimore)*
- Moderator:** *How about health insurers?*
- Participant 1:** *Well you know they have it, the data.*
- Participant 2:** *They have it.*
- Participant 1:** *Because each time you take a shot they have to pay the claim so they have all the records.*
- Moderator:** *How do you feel about that?*
- Participant 1:** *It's not your choice, they just have it whether you like it or not.*
- Participant 2:** *Their system is big. (Korean higher education, Pasadena)*

Participants did not want marketing companies, employers, people who do not work in the medical field, and the general public to have access. A consistent theme in all the groups was the fear that the information in the database cannot be adequately safeguarded. Participants continued to voice concerns about access that were already raised in the discussion about content, and several participants expressed that they would like to provide a list of authorized users of the system to the state in order to keep estranged spouses and the general public from accessing their child's records.

A signed authorization is a good idea. 'You have my written permission to call the registry.' (Non-Hispanic white lower education, Portland)

No, because who knows maybe they go to the doctor's to get their records and try to steal your kid. (African American higher education, Baltimore)

So then you just give up all the information and when it comes down to the employer he can say, 'Well, I see he was treated for AIDS, we can't hire you.' (African American lower education, Portland)

Participant: *Strangers, strange people.*

Moderator: *Define strange people.*

Participant: *In my case, the father of my first daughter. For me, he's a stranger, because I haven't seen him and it would bother me. With this information he might...(Hispanic lower education, Tucson)*

Moderator: Who else? How about extended family, grandparents?

Participant 1: Only if they have partial custody or something like that.

Participant 2: Well, if you are on vacation, you know, it would be good for them to see it.

Participant 1: That is when you leave a letter stating I give my permission. (Hispanic higher education, Tucson)

Participant 1: You know insurance salesmen, drugs and nutritional sales people. People in the health circle but who are not relevant.

Moderator: So sales people. You mean like the sales reps?

Participant 1: Right, they want to sell you insurance policies, so they want to know information about you. Their purpose is moneymaking. But I don't need their help so then they cannot get information from me.

Moderator: So companies right? Business. What other people shouldn't have access to the information? What organizations other than medical organizations?

Participant 2: People who have nothing to do with this. If information is helpful to the child, so people who are not relevant to the medical field. (Cantonese Chinese lower education, Pasadena)

3.3.3 Reactions to Links to Other Health-Related Databases

The idea of linking the registry to other health care databases, such as those kept by WIC and Medicaid, received mixed reactions. For several, this was one of the most difficult issues for them to understand, and they could not easily form an opinion about why they should or should not be linked. Others supported linking the systems because they saw it as a way to improve the health of children by making it more convenient for those organizations to share information. A few who were generally supportive said they could endorse the idea as long as the child's name and address were not included. Reasons for not linking the database included fear that information is being made available to too many people and concern about being labeled or segregated as a recipient of public assistance.

Maybe there could be some way those types of registries could access it but not get their personal information, but they could still use the medical information (Non-Hispanic white higher education, Baltimore)

Participant 1: To me the stuff on here is not secret. It's not a big deal. It's not like you are trying to hide or you don't want people to know.

Participant 2: It saves you from having to answer so many questions. (American Indian lower education, Tucson)

Participant 1: I feel as though it's too much information being passed onto different links. It is going through too many hands.

Participant 2: It's a privacy issue.

- Participant 3: In my opinion, that's getting away from the central purpose of the registry. I think that is a bad idea. (African American higher education, Baltimore)*
- Participant 1: I think it's OK.*
- Moderator: Why do you think it's OK?*
- Participant 1: Because this is nothing secret. It's about my child, how many vaccinations he has. I don't mind if those Medicare organizations know the information.*
- Moderator: Basically they would be linked by computer to access this database.*
- Participant 2: That's very simple, no problem. The full name, date of birth.*
- Moderator: So you don't see any problem with it?*
- Participant 2: No. (Mandarin Chinese higher education, Pasadena)*
- Participant: I feel, when you say other systems like such as WIC or Medicaid, I mean that's fine but I think our main concern, or my main concern is that this does not go out to any vender or anyone in particular, that's a private company that will call you or who will harass you, 'What, you did, you provided this? But we have something else that's going to be cheaper, other insurance.' We, I don't want that. You know, if it has to do with my children's health, it's fine, but I don't want no one calling me or sending me anything in the mail that they have something better.*
- Moderator: We're referring really to, you're making the clarification, it needs to be something related to really the health of your kids?*
- Participant: Exactly. (Hispanic lower education, Miami)*

Among all 20 groups, the Korean participants reacted the most negatively to the idea of linking the registry. The notion of linking seemed to decrease their comfort level with the whole concept of the registry. Their major concern was that too many people would have easy access and insurance companies would use the information against them in the future.

- Moderator: How would you feel if you knew the registry might be linked by computer to other systems that have information about health? For example, Medi-Cal system, WIC system or a system that tracks screening for lead poisoning, how would you feel about this registry being linked by computer to that kind of stuff?*
- Participant 1: Even more insecure.*
- Participant 2: Going into somebody else's medical information, if one is linked to the other, if somebody could link the other end it's obvious he has access to this end, so if something is linked together it's like it's open to everybody. (Korean higher education, Pasadena)*

3.4 Consent and Inclusion

For this part of the discussion, the moderator began by introducing the topic of how information gets into the registry. He or she explained that states have different laws and policies regarding the sharing of information and participation in registries and then continued with a description of the three most common ways that states deal with these issues (see Section IV in the moderator's guide in Appendix C for a full description). The three different approaches were described, and each one was discussed separately. For each approach, the moderator would begin discussion of a scenario by saying, "Suppose you live in a state which (fill in approach)." She or he would describe the approach again and ask participants how they would feel about living in a state that implemented the law or policy in question.

3.4.1 Reactions to the "Opting Out" Approach

The basic description of the approach was: *Information is not included in a registry until parents have been notified that they have the opportunity to decide if the information should be included. The information will be included if the parents take no action.* Many participants immediately noted several drawbacks to the opting-out approach. Although the moderators did not specify how parents would be informed that they have the choice to opt out, participants assumed that opt-out cards would be sent in the mail. They feared the cards could be lost in the mail, sent to the wrong address, thrown out with junk mail, or lost in a pile of paperwork. Most participants perceived this approach as a loss of some personal control over decisions regarding their own children.

It would be my decision if I decided I didn't want to do that. I just want my decision and my consent. (African American higher education, Miami)

I'm going to have to do some digging because I'm going to be hotter than snot if they go ahead and take my kids' information and I don't have a chance to opt out. I probably wouldn't opt out but it would be something that would make me mad. (Non-Hispanic white lower education, Portland)

What if the mail never makes it to your house...without your consent and they just assume that you wanted it. (American Indian higher education, Tulsa)

I think everybody should be allowed the choice whether or not they want to participate. Either they do or they don't and with this [approach], it does give us a choice, but it gives us a choice in a backward type way. (Non-Hispanic white lower education, Ankeny)

Participants in several groups recognized that this method of enrolling people in the registry would be advantageous to those administering the registry. They believed most parents would ignore attempts at notification and, therefore, more children would stay in the registry than would if another

approach were adopted. Others saw the opting-out approach as a benefit for children, reasoning that the parents who are least likely to follow the immunization schedule will probably not bother to opt out of the registry. If these parents do not remove the child from the registry, they will receive immunization reminders and may be more likely to get the child immunized. When the moderators asked for a show of hands to see how many in the group would choose to opt-out if presented with the choice, an extremely small minority said they would choose to do so.

It's almost like a fail-safe net where if you do it fine, if you don't do it fine, there's still that safety net to catch the child. (African American higher education, Miami)

Participant: *It seems like in today's society everybody has got so many things on their mind and rushing all time, in other words, I think it's positive that it defaults. We're talking about immunization here so it seems like to me that it would be advantageous to default, you know to go ahead and automatically put your child in there without the parent having to do anything. If a parent is really upset or doesn't want it, then they can go ahead and take action but it seems to me that it's beneficial for the child and beneficial for the parent, because it automatically defaults to that.*

Moderator: *So you're saying this is an advantage to make it easier?*

Participant: *Yes, that's the way I see it. (Hispanic higher education, Miami)*

Participants in three of the four Hispanic groups and in both of the American Indian groups in Arizona were most consistently comfortable with the opting-out approach, though issues of parental rights and control still surfaced.

A lot of parents don't do anything. They put things off and this way it's automatically done. And if they really, really care about if it's in there or not, they will go in and sign the form or whatever they need to do. If it's automatically done, I think it's best. (American Indian lower education, Tucson)

I like it because it assumes for the benefit of the child. So if a parent is really opposed to it for religious or other kinds of reasons that they don't want to be part the system, then they will make more of an effort to be out of it. But if it's because of ignorance that they don't know about immunizations, then they're not going to make an effort to sign an opting-out form and so they will be included in this. And that's my concern, people who do not immunize their children out of ignorance more than knowing and making a decision not to participate. (Hispanic higher education, Tucson)

3.4.2 Reactions to the "Consent" Approach

This approach was defined as: *All parents must give explicit permission before a child's immunization information is included in the registry.* Most participants favored this approach. They felt

this approach is better, because it gives the parents direct control over information about themselves and preserves their right to make informed decisions about their own children. Yet some participants who preferred the approach also saw the possible risk that children will be excluded from the registry if irresponsible parents do not take the time to read, sign, and return consent forms. Others voiced concerns that if forms get lost in the mail or misplaced in their homes, they would never have the opportunity to give their permission.

Like I said a lot of mail goes through and you don't want to take the time to say, 'oh, I don't want this' and a lot of people just throw it away. I mean if they don't want to take their kids for immunizations, why would they write and send it back? (American Indian lower education, Tulsa)

I would prefer the consent approach, but I can understand why the State would do the opt out approach. (Non-Hispanic white higher education, Baltimore)

I like having the power to make decisions. (Hispanic higher education, Miami)

If you have to obtain consent, it's a conscious decision [but] the system would not be effective if there aren't many names in it. (Non-Hispanic white higher education, Ankeny)

Participant 1: I gave you permission. It's like you felt you had a part of it. When you sign a consent they're saying, 'OK, you're listening to me.' I'm your boss now so if you don't sign it, they [aren't] going to [include your child].

Participant 2: Makes you feel important.

Participant 3: If I was to be selfish, that's the [approach] I would choose, consent because I know I would send it back but to think of the general public, I would say that's not a good [approach] because I don't think those that need to respond would respond. (African American lower education, Baltimore)

The majority of participants said they would give consent to include their child's records in the registry if they were presented with the choice, but a few added that any mailed requests for consent should be followed with at least two or three reminders in case the first one gets lost. Of the small number who said they would not give their consent, the basis for their decision was that they were still too uncertain about what information would be listed and who would have access.

I like this because I feel I am respected by them. I feel that I can make my own decision. I feel that if they can notify us, not just only one time, but two or three times at least, then I feel this is good for me. (Mandarin Chinese higher education, Pasadena)

I would go with [the consent approach] because if you are responsible you'll make sure that you do it — it would be a necessity, something you had to do. (African American lower education, Baltimore)

Without understanding it, you know, I would not want to be on it because if I don't have full information on it, if I don't understand it completely before the record is on the registry. But if I understand it, then I wouldn't mind to have it [entered]. (Cantonese Chinese lower education, Pasadena).

Overall it's a good idea. I need more information on the what, where and when...(Non-Hispanic white higher education, Baltimore)

3.4.3 Reactions to the "Automatic" Approach

The final approach was defined as: *The law or health policy requires that the information be included in a registry. Parents do not have the chance to give their consent for their child to be in the registry.* The majority of participants were least comfortable with this approach. Participants perceived this option as taking away their control over the release of personal information and their right to make decisions for their children. Because they felt that this approach takes away their rights, a few participants characterized it as “un-American” or “too controlling.”

Now this is against the American spirit. This is very un-American. So this is by force, right? Because in this country, I think a lot of people would disagree with that. (Cantonese Chinese lower education, Pasadena)

Participant 1: It takes away all your rights.

Participant 2: People don't like being made to do stuff or being told you have to do this. (Hispanic higher education, Tucson)

I wouldn't want my choice taken away. You're invading my rights. I want to be able to say yea or nay, would it be by letter, phone, by doctor, by whoever, I want to say yea or nay. (African American lower education, Portland)

That's too controlling. That's like telling you you don't have the option. It's like saying you have to spend the rest of your life in this room. It's going to start there and go somewhere else. (Non-Hispanic white lower education, Ankeny)

Participant 1: I'd move.

Participant 2: It's a Big Brother issue. (American Indian higher education, Tulsa)

A different tone emerged in the Mandarin Chinese and Vietnamese groups. Individuals in these groups strongly favored the automatic approach and felt that the other two approaches required too much paperwork and were a waste of time. Some expressed that America has a wonderful health care system that cares deeply for the children of this nation and that the automatic approach is clearly beneficial

for all children. A few individuals in groups other than the Mandarin Chinese and Vietnamese said they would accept this approach because it is best for the health of the public. They argued that the approach, the registry would cover the most children and would be most likely to include those children whose parents do not have them immunized.

I like the third approach, no choice everybody should be in. (Mandarin Chinese higher education, Pasadena)

Participant 1: It's even better. No one is an exception here. One's health, that's always a good program.

Participant 2: Freedom is good but too much freedom is bad. Let's say I have a child, immunization or no immunization, there's also a freedom to do that but for example, if my child has like rubella or disease, [it may be a] contagious disease that makes my neighbor suffer and that's not good. (Vietnamese lower education, Pasadena)

3.5 Closing

As the groups concluded, the moderator reviewed the topics that had been discussed. Topics included what an immunization registry is, what information it contains, who has access, and how the information gets into the registry. He or she then asked the participants to summarize what they felt were the most important benefits of the registry, what their biggest concerns were about the registry, and whether their health care provider's opinion of the registry would affect their decision about immunization registries. Prior to the moderator stepping out of the room to see if any observers had additional questions, he or she asked participants to write down on the pads of paper in front of them what they would like to say to the people working on the registries.

3.5.1 Most Important Benefits

Participants consistently named convenience of having immunization information in one place as a main benefit of a registry. If parents lost their own records or changed doctors, they could retrieve records through the registry. A substantial number of participants felt as though the registration process for day care programs and schools would be much easier and faster if the schools were able to access the children's immunization data immediately from the registry. Another commonly mentioned benefit was the decreased chance of a child receiving duplicate vaccines. From a public health perspective, several parents felt the registry would help children whose parents would not otherwise have them immunized. And a few saw the benefit to having researchers have all the information readily available for analysis purposes. In addition, many participants felt that including the vaccine lot number and the name of the company that made the vaccine would benefit parents whose child had received a recalled vaccine.

If they have access to the medical records, they won't get a shot with the wrong medicine he might be allergic to. (African American lower education, Baltimore)

The good thing I see about it, there are so many children out there who are not immunized and you know I think basically what they want to do is keep track of it and get these kids immunized because they are coming up with all these diseases and they are trying to prevent diseases. (African American higher education, Miami)

One benefit for me because I carry all the immunization cards with me and my husband doesn't have a clue as to what my kids have, if you had something like this and I wasn't available, my husband wouldn't be going, 'oh, I don't know, I don't know.' Here it is right here. (American Indian higher education, Tulsa)

I do like it if I could get access [to] the lot number and the company if there was something wrong and also if my doctor's office had this and I lost my card, I might get a copy. If they could—boom—get me a copy, push a button and print it out and I'd pick it up. (Non-Hispanic white lower education, Ankeny)

I think the easy access to the information if you change doctors. (Hispanic higher education, Tulsa)

Participant: Public health and convenience.

Moderator: Why public health?

Participant: Definitely there's some kind of controlled method to preventing some disease that could be preventable going through this registry is something pops up, gives a little red signal on this little child that he didn't go through this important immunization and it could be preventable. The polio is gone but some negligent parents just neglect the child and don't get him the proper immunizations, so he could spread the polio again and contaminate the whole community. (Korean higher education, Pasadena)

3.5.2 Most Important Concern/Biggest Risk

Participants most commonly named the possibility of a breach in confidentiality and privacy as the issue about which they were most concerned. Most participants had serious questions about who would have access, especially if their address, phone number, and Social Security number were included in a registry. Several participants mentioned that they were concerned about health insurance companies getting access and possibly denying coverage to those not adequately immunized. A few mentioned their worries about non-custodial parents getting access to their address and phone number. Other concerns were inaccuracy of information and the amount of money needed to support the registry. Some expressed concerns about how difficult it would be to correct errors and the hassles they would have to endure trying to have their child's record corrected.

I'm thinking like maybe the insurance company gets hold of it or something. I don't know what they'd do, who knows? Somehow I guess we have to pay for it and end up paying more. (Mandarin Chinese higher education, Pasadena)

I was going to say there might be cases where a parent or the mother might be with the child legally and they do not want the other, the parent or the mother to know of the whereabouts of [the child]. If they, you know, if they have access to that again, giving address and phone number, they could track down where this child is at. (Hispanic higher education, Miami)

That my kid could die because they didn't put in the record a shot he got or something, or that they put in the wrong shot that he didn't get. Or something like that. Some kind of mistake. (American Indian higher education, Tulsa)

I don't want to give you my child's name that you can pull up his entire history when he is 18. (African American higher education, Baltimore)

Participant 1: The privacy thing would be a concern. I guess we shouldn't act like we're all paranoid or anything like that but when you see shows that tell you [what can be done with information about you]...I mean I can see how it's a benefit for the schools...[but] it has to benefit some kind of research too - medical research. If it's just a vaccination registry, I can't see creating this whole bureaucracy.

Participant 2: I'm a little bit concerned about the cost of putting this all together. It's all going to come down to the taxpayer. This information will be useful. If there is enough information to be useful for research, I'm for that. (Non-Hispanic white higher education, Baltimore)

If time allowed, the moderator probed for concerns about law enforcement with regard to immigration and naturalization issues. These issues seldom emerged unsolicited, yet when discussed, participants expressed mixed reactions. Many did not understand why law enforcement officials would need the information, while others felt neutral to positive about such access. In groups where the topic had not been previously discussed, the moderator also probed for concerns about entry to school or day care programs being denied if the schools and day care programs had direct access to the registry. Participants did express some concern about the issue, but most of these participants said they immunized their children and that they would not have to worry about it. They did mention the benefit of having children who are not immunized banned from school or day care. They felt that keeping sick or infected children out of school would help keep their children healthy.

That's why they want to do this registry because then it can verify also whether this child was born here or not. I think the reason why all of this is coming up anyway is because they want to know who is and who isn't legal in the United States because now you got a lot of people who come over. (African American lower education, Portland)

To me immigration and Police Department, they shouldn't want to have information like that. What do they need to know about information about the child? Why would they go through all the trouble? (Cantonese Chinese lower education, Pasadena)

It would be [a concern] if you were here illegally. If this registry had information and they couldn't hold it against you, then fine. If they track you down and ship you back. Oh, no. (Hispanic higher education, Tucson)

Participant 1: Well, half has to do with immigration anyway, they're going to look for it anyway. Everything has to do with blood or whatever.

Participant 2: There are parents that do not have, that are not legal and they don't want to take their kids to be vaccinated. (Hispanic lower education, Miami)

Participant 1: That's fine for me but I don't see any point why they (law enforcement) need this for.

Participant 2: Immigration office will not let you come into the country if you don't have the record. Of course they should know. (Mandarin Chinese higher education, Pasadena)

Of course they (schools) ask for that information. You have no reason to cheat them. You don't want other kids to lie about a record, which is eventually going to affect your kids' health. (Cantonese Chinese lower education, Pasadena)

That's a good reason. If you didn't get shots, you cannot be accepted into school. (Mandarin Chinese higher education, Pasadena)

3.5.3 Influence of Health Care Providers' Opinion of Immunization Registries

When asked if their doctor could influence their decision to participate in the registry, most said that their doctor's opinion would be influential. Of these people, several suggested that while they would consider their doctor's opinion, it would be only one source of information, and that other opinions would be needed before they made a final decision. Some indicated that a doctor's opinion would not influence them at all. In three of the four Hispanic groups, the majority of participants said their doctor's opinion would influence their decision little if at all.

I think this is a parent's decision. It's not like a kind of disease I don't know then I have to follow the doctor's advice. I know clearly I know better than the doctor even. Serious. (Mandarin Chinese higher education, Pasadena)

Maybe to hear their reasons why they wouldn't want it. To me, that would be important. Maybe there is a good reason why it's not and we haven't heard about it or thought about it for it to make sense. And if they had something to make sense, maybe we would want to listen to that. (American Indian lower education, Tucson)

Participant 1: *They're giving our children shots, they're looking at our children. We trust them to say our children are healthy or he's got pneumonia or whatever.*

Participant 2: *We trust our doctors. (African American lower education, Portland)*

You don't see the same doctor everytime so you don't have a relationship. (American Indian higher education, Tulsa)

I make my own decisions but if [the doctor] said something negative, it would make me wonder. (Non-Hispanic white lower education, Portland)

Not that much weight. If I thought it was something I needed to do I would do it. (Hispanic higher education, Tucson)

With me, I know my wife knew this doctor from when other children in her family were growing up. Because of that, we chose this doctor for my son. And she's been a lot of help and answered a lot of questions and stuff like that. And even when she was out sick, we called her at home to ask her opinion of the doctor that was replacing her. (American Indian higher education, Tucson)

Participant 1: *No, no. I always want a second opinion.*

Participant 2: *No, I decide what to do in that case. I'm the one that decides with my children. (Hispanic lower education, Miami)*

3.5.4 Suggestions/Comments to the People Working on the Registries

Upon re-entering the room, the moderators asked participants what they had written down as their suggestions or comments to the people working on the registries. The majority of respondents across all 20 groups wrote down at least one of the following three suggestions:

- make sure the information is accurate and updated frequently;
- make sure only authorized people have access; and
- respect the rights of parents and let parents decide if they would like to participate.

Many also expressed their desire to know exactly what information was going to be listed and who would have access prior to giving or not giving their permission to have their child's records included. Other suggestions included "please include allergic reactions" and "hard copies should be provided to parents."

Keep everything confidential unless otherwise authorized. (Non-Hispanic white lower education, Portland)

I put I would be for the registry only if I could give my permission and know exactly what was on it and who exactly wanted to know the information before I give them permission to have the information. (American Indian higher education, Tulsa)

Participant 1: I wrote 3 requests. The registry should be as universal as possible for the benefit of all kids, information on the data base should be used for health reasons only, and participation on this should be mandatory for all kids in public schools.

Participant 2: Pretty much to be accurate and to always specify if a child has any allergies and keep the parent up to date with the vaccines. (Hispanic higher education, Miami)

The people responsible for this registry would have to respect the rights of parents, parents' wishes and respect family privacy. This needs to be presented as an aid to parents and not as an invasion of privacy by the State. (Non-Hispanic white higher education, Ankeny)

Ensure beyond a reasonable doubt that the information put in is in fact used for the purpose intended and by whom or be expected to suffer the consequences. (African American higher education, Miami)

An immunization registry will benefit the people because of reminders about immunization; ability to retrieve records that are lost or stolen and for information for research. My biggest concern is who can change or add information (American Indian higher education, Tucson)

Of all the groups, the most excited about the implementation of the registry system were the Vietnamese, Chinese and lower educated Hispanic participants. Frequent comments from these participants included "get it going" and "make it mandatory for all." Many in these groups commented that the registry is a great idea and will be very beneficial to all children.

This should be mandatory for everyone and that it should be private in certain information. (Hispanic lower education, Miami)

The first thing I want to say is I feel this is a very good system. It's good for the general public because it makes them recognize the importance of their health, not only that it's good for the family, but it's good for society. For myself I would like to thank American society. I find this country; it is so good here. When you compare with other societies, you know [when] children are sick, [there are] no medications and in this country you know they take care of people and it's very good. (Vietnamese lower education, Pasadena)

I think they should make this a unified system and like make it mandatory actually. People should just register, but only the doctors, family physicians; those people have access to it. (Mandarin Chinese higher education, Pasadena)

SECTION 4. CONCLUSIONS

4.1 Limitations

Although the results from the present study provide useful insights into the issue of how parents feel about the concept of immunization registries and the key issues of content, access, consent, and inclusion, the data are limited. Several features of the study must be addressed in order to put the findings of the focus groups into proper perspective.

4.1.1 Representativeness of the Sample

As stated in the Method section (Section 2.1) of this document, the people who participated in the focus groups were not selected through a probability sampling procedure. Once the research questions guided the development of profiles of the types of people who should be included in the discussions, recruiters contacted and screened individuals who were already listed in the individual focus group facility a database and most likely to match the criteria for selection. Recruiting efforts by the marketing research facilities ceased once quotas were met.

Because they were carefully screened, we know that all of the participants had the appropriate life experiences to be able to thoughtfully articulate their views about the issues (e.g., all of them were parents or legal guardians who had at least one child under the age of 6). At the same time, however, there is no reliable method of estimating how representative their knowledge, attitudes, beliefs, and opinions are of the rest of the population (even one that is narrowly defined). For example, if four Hispanic women in the Miami agree that their child's Social Security number should not be listed in the registry, we cannot say with any degree of certainty whether their view represents the majority or the minority of other urban, Hispanic women around the country. Perhaps only 5,000 others with the same characteristics would agree, or the number might be 500,000.

Focus group data are a very valuable source of information, but they should not be used as a substitute for data obtained through probability sampling techniques. Focus group results can complement the latter form of data; they can provide great insight into how people think about issues; and they can offer significant assistance in determining how to target and develop campaigns. But one should not expect focus group data to provide the definitive answer to any question.

4.1.2 The Focus Group Setting Versus Real Life

In any social scientific study, the researcher always wonders if the opinions, attitudes, and/or stated intentions of respondents reflect reality. That is, when respondents provide answers to questions, are they honest with themselves and the researcher, and can they accurately predict their own behavior when presented with hypothetical situations? This uncertainty exists even for studies that use probability sampling techniques. For example, if the results from an appropriately drawn national random sample of 1,500 parents with young children indicate that 96 percent of all respondents claimed that they will follow the prescribed schedule for immunizations, then one can assume with a high level of confidence that approximately the same proportion of parents in the general population would give the same response. But with what level of confidence can we say their behavior will match their intent?

The same problem exists for focus group studies. In a sense, a focus group is an unnatural situation in which people have the opportunity to express opinions and reach decisions after 2 hours of guided discussion with the moderator and other group members. Seldom in real life do people have the chance to decide an issue with the equivalent luxury of time and shared information. If asked to make a decision about the same matter in a different environment with less time to do so, the response might be different.

Also, a focus group is a forum in which people have the chance to speak their minds with impunity. The context is one that often gives a feeling of empowerment to people who may not typically feel very powerful. This tends to be true especially for individuals like many in this study who are members of a minority population, have a limited education, or both. The sense of power can receive an even greater boost when the participants know that the research relates to institutions (e.g., state governments) with which they typically feel powerless in their daily lives.

With these factors in mind, the researcher must always interpret focus group data by carefully considering the context in which comments were made. This does not suggest that participants have not told the truth, but the researcher would be wrong not to consider the ways in which responses can be colored by the setting in which they were made. Researchers need to look to consistency and nonverbal behavior as clues to supporting evidence.

4.1.3 Need for Information about Other Key Issues

In trying to determine what information parents are comfortable with having listed in the registry, who they are comfortable with having access, and how they would like to be notified of inclusion

in the registry, the opinions of several populations are needed to obtain a more complete view of the situation. In this study, we successfully gathered information from several key groups about a number of different issues. We had the opportunity to hear the views of parents from different parts of the country with varying levels of education. Also, we talked to individuals from five different ethnic groups, people who live in both small cities and large urban environments, those who do not speak English or are bilingual, and both men and women.

However, we still lack information about other populations and issues relevant to immunization registries. First, all of the participants in the groups had at least one young child for whom they made health care decisions, but we have no data from people who currently have no children but who may be parents in the near future. For future parents, the concept of immunization registries may not have immediate importance to them because they would have no experience for comparison. However, their views still could be very insightful.

Second, we have no data from physicians and other health care providers. The immunization process, at least at the time that vaccinations are administered, involves two distinct parties--those who seek to have their children immunized and those who provide the health care. Knowing the opinions that health care providers have about immunization registries, how the registries affect their practices, and how they would communicate the concept of immunization registries to parents could be as important as understanding how parents feel.

Third, immunization registries have economic ramifications that this study did not address, and clearly, there were questions from many participants about the cost to the taxpayer. We did not present any information to the participants about the potential costs of training people to use the system, keeping the information in the system updated, or maintaining the computer system. If they knew what registries might cost taxpayers, would they be as willing to participate?

4.2 General Conclusions

After one examines the data as a whole in the context of the study's limitations, the issue then is determining what we learned from these participants. In general, if access is limited and the information included directly relates to immunization issues, there is little evidence that parents would not agree to participate. Without doubt, the most compelling data that lead to this conclusion are the results from the informal votes taken at the end of the group discussions. Moderators took votes to see how many would opt out if they were presented with the choice and how many would give their consent if requested to do so. The overwhelming majority said they would not opt out and/or they would give their consent. Of these

participants, many stated that the registries are a good idea and are very convenient, provided that the information is safeguarded and is used for the intended purposes. The strongest and most consistent support for immunization registries came from the Asian/Pacific Islander and Hispanic groups.

Certainly, there were a few participants in the groups, especially among American Indians and African Americans who either wavered in their willingness to participate or consistently rejected the idea of a registry. Examining the comments of these participants in isolation could lead one to the initial conclusion that they would strongly resist any attempt to have their children's immunization data included in a registry. One might even argue that several would take a very defensive stance and ignore the immunization regimen altogether if they felt that their children would be forced to be included in a registry that they find unacceptable.

We cannot say for certain that none of the participants would prevent their children from being included in the registry if provided the option. However, information culled from the various parts of the group discussions leads us to believe that if parents are notified of what information will be listed and who will have access, and if they themselves are given the opportunity to give their permission for inclusion, then almost all of the children of the participants in the study would be included in the registry. Parents gave several reasons to support this conclusion.

First, the general discussions about things a registry can do consistently indicated that the participants felt immunization registries are a good idea. Most parents' number one concern is the health and safety their children and they will do whatever they believe is within their power to ensure that their children are in good health. In the case of immunization records, participants noted the convenience of the registry. They indicated they would receive timely reminders to ensure that their child would receive the appropriate vaccines at the appropriate times and all the records would be kept in one place for safe keeping, decreasing the chance of lost records and the administration of duplicate vaccines.

Second, the parents as a whole recognized the value of immunizations. Several mentioned parental responsibility as a reason they have their child immunized. These participants felt as though it was their job as parents to keep their children as healthy as possible and that immunizations are a necessary component of a child's medical care. Anything that would increase the accuracy of their records, allow for tracking if a bad batch of a vaccine were used, and/or decrease the amount of work on their part (e.g., registration for school, remembering when the next vaccine is due) would be a benefit to them and their children's health. When the topics of information content and access were discussed, several participants mentioned that if only immunization data were shared, they would be happy to participate. Many described immunization data as harmless and beneficial to the overall health of all children.

Third, and perhaps most important, participants had many unanswered questions on information content, who would have access, and how the information would be used and shared. The focus groups were not an attempt at persuasion. Instead, the moderators tried as much as possible to present in a neutral fashion the concept of immunization registries and the choices the registries offer to parents, including approaches to inclusion. The moderators did not advocate for one approach over another, nor did they present any of the information about content or access in a positively or negatively skewed light. And as is standard practice in focus groups, the moderators answered only the most basic questions posed by the participants. Therefore, there were many unanswered questions about registries in general and about the operation of registries in the specific states in which participants live. Had participants been provided more detailed information or had an opportunity to have all of their questions answered, or had the information presented to them by an authority figure, then even those few who had serious misgivings might have endorsed the use of registries.

In no way do we want to ignore, invalidate, or minimize the comments made by the small minority of participants in the focus groups who said that they were reluctant to have their children's information entered into the registry. To do so would show a lack of respect and would be a foolish disregard of the valuable insights they provided. We must assume that they voiced their concerns to the idea of immunization registries in all sincerity. However, hardly anyone who expressed a negative position presented his or her opinion as immovable.

Appendix A

Map of Focus Group Sites

Appendix B

Focus Group Screener

Appendix C

Moderator's Guide (English and Spanish)

Appendix D

Focus Group Visual Aids (English, Spanish, Cantonese, and Vietnamese)

Appendix E

Moderators' Topline Summaries